People with developmental and intellectual disabilities: community living and health care experiences

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Part 1: Definition of Persons with IDD
What defines Intellectual Developmental Disabilities

- DSM-4: IQ at or below 70
- DSM-5: More holistic view
  - Social skills, ability to perform ADLs, Reasoning, Learning, etc.¹
- Onset during ‘developmental’ years
- Can occur concurrently w/ physical disability (American Psychiatric Association, 2000)

In 2016 10.7% of Massachusetts residents living in the community had some kind of

**Massachusetts Residents by Disability Category** (ages 18-64 living in the community)

<table>
<thead>
<tr>
<th>Disability Category</th>
<th># of MA Residents</th>
<th>% of MA Residents</th>
<th>% of Disabled in MA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Disability</td>
<td>191,579</td>
<td>4.4%</td>
<td>48.7%</td>
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<tr>
<td>Ambulatory Disability</td>
<td>177,389</td>
<td>4.1%</td>
<td>45.1%</td>
</tr>
<tr>
<td>Independent Living Disability</td>
<td>148,689</td>
<td>3.4%</td>
<td>37.8%</td>
</tr>
<tr>
<td>Self-Care Disability</td>
<td>69,086</td>
<td>1.6%</td>
<td>17.6%</td>
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<tr>
<td>Hearing Disability</td>
<td>68,467</td>
<td>1.6%</td>
<td>17.4%</td>
</tr>
<tr>
<td>Vision Disability</td>
<td>62,365</td>
<td>1.4%</td>
<td>15.9%</td>
</tr>
</tbody>
</table>

(MA Rehabilitation Commission, 2016)
How do we address people with IDD?

× Don’ts:
  - Refer to a person as mentally retarded or handicapped
  - Focus only on the person’s disability
  - Speak only to the parent/aid/caregiver, ignore the person w/ IDD, act demeaning/condescending

✓ Dos:
  - Use PERSON FIRST directives
  - Focus on what the person can do
  - If speaking to a person w/ IDD:
    ○ Speak to the person first
    ○ Use their name
    ○ Incorporate into conversation & decision making processes as much as possible
  - Ask the person how they refer to their condition
Clinically relevant needs

● General
  ○ Constipation (40%)²
  ○ Mental illness (31%)²
  ○ Epilepsy and seizures (up to 40%)³
  ○ Polypharmacy (up to 40%)⁷
  ○ Mortality³
    ■ Aspiration pneumonia (19x more likely)
    ■ Septicemia (3x more likely)
    ■ Influenza and pneumonia (6x more likely)

● Syndromes (30% of IDD population)
  ○ Down Syndrome⁴
    ■ Hearing and ocular problems (up to 50%)⁴
    ■ Hypothyroidism (15%)⁴
    ■ premature dementia and Alzheimers (20% by 40, 50% by age 60)²
    ■ Osteoporosis and musculoskeletal disorders⁴

http://md2jupiter.com/the-dangers-of-polypharmacy/
Social Risks

● Legal
  ○ Guardianship
  ○ Human Rights

● Sexual health
  ○ Educate patient on sexual health, STIs, consent, abuse and substance use

● Abuse
  ○ 60% increased risk of experiencing interpersonal violence\(^2\)
    ■ Physical, sexual or caregiver abuse
    ■ Neglect
  ○ Mandated Reporting
    ■ Reasonable suspicion
    ■ Disabled Persons Protection Commission (DPPC)
      ● Ages 18-59
Disparities

● Access to Healthcare
  ○ Limited to no formal training for providers
  ○ Lack of accessible facilities or appropriate instruments

● Poorer health outcomes, mortality, morbidity and quality of life
  ○ Life expectancy 15-20 years shorter than general population\(^3\)
  ○ Lower rates of preventative care and screening
    ■ Mammography (59.6% screened versus 84.9% MA general population)
    ■ Colorectal cancer (17% screened versus 21% general population)
  ○ Oral Health
    ■ 32.2% untreated caries, 80.3% periodontitis, 10.9% edentulism\(^6\)

● Research Gap
  ○ Exclusion of participants with IDD
  ○ Few studies focusing on IDD population
# Service Project

**Massachusetts Department of Developmental Services Adult Screening Recommendations 2017** updates to 2014 **revision**

The following are global screening recommendations for adults with intellectual/developmental disabilities. There may be other risk factors not identified here. Always consult with the Health Care Provider (HCP).

<table>
<thead>
<tr>
<th>Procedure</th>
<th>19-29 Years</th>
<th>30-39 Years</th>
<th>40-49 Years</th>
<th>50-64 Years</th>
<th>65 Years +</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Maintenance Visit</td>
<td></td>
<td></td>
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<tr>
<td>Oral Health Visit</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Annually</td>
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<tr>
<td>Promote dental health through regular oral hygiene practices, assessment by a dentist at least every 6 months.</td>
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**Labs and Screenings**

**Cancer Screening**

- **Breast Cancer**
  - Screen every 3 yrs if ages 21-29.
  - Screen every 2 yrs if ages 30-39.
  - Screen annually if ages 40 and older.
  - Women with a family history of breast cancer should consider mammography every 1-2 yrs at ages 20-25.

- **Cervical Cancer (Pelvic Exam & Pap Smear/HPV)**
  - Screen with Pap test every 3 years, or combination of Pap and HPV tests every 5 years, for women who want to lengthen the screening interval.
  - Discontinue Pap test after age 65 if there is documented evidence of consistently negative results.

- **Colorectal Cancer**
  - Not routine except for patients at high risk.
  - Age 50 (until age 75), select one of the following methods or screening intervals: annual FOBT (Fecal Occult Blood Testing), Biennial sigmoidoscopy every 3 yrs, FOBT every 5 yrs, sigmoidoscopy every 10 yrs.

- **Testicular and Prostate Cancer**
  - Annual testicular exam for all male patients.
  - Testicular ultrasound if at high risk.
  - Review screening and testing options for prostate and testicular cancer starting at age 40 for men of African-American descent, at age 45 for all other high-risk men (brother or father diagnosed with prostate cancer before age 65), and at age 50 for all other men.
  - PSA screening is not recommended for ages 70+.

- **Skin Cancer**
  - Annual screening for those at high risk (history of skin cancer, a lighter natural skin color, blue or green eyes, blond or red hair, history of sunburn tanning or sunburns, and people who have taken immunosuppressive medications).

**Additional Recommended Screening**

- **Obesity**
  - Screen for overweight and eating disorders. Consult the CDC's growth and BMI charts. Counsel on benefits of physical activity and a healthy diet to maintain desirable weight for height. Offer more focused evaluation and intensive counseling for obese adults (BMI > 30), or overweight adults (BMI > 25), with co-morbidities to promote sustained weight loss.

- **Hypertension**
  - At every medical encounter and at least annually.

- **Cholesterol**
  - Screen with lipid profile panel at age 35 and older if not previously tested.
  - Screen women age 45 and older if at increased risk for coronary heart disease.
  - Screen every 5 yrs or at clinician's discretion. Screen for individuals at increased risk (family history of heart disease, diabetes, tobacco use, hypertension, obesity, and use of psychotropic medications).

- **Diabetes (Type 2)**
  - Screen at least every 3 yrs with the hemoglobin A1C or fasting plasma glucose screen until age 45 for individuals who are at high risk (obesity, family history of diabetes, low LDL cholesterol, high triglycerides, hypertension, sedentary, and for African-, Hispanic-, Native-American, Asian).
  - Screen every 3 yrs beginning at age 45.

- **Liver Function**
  - Annually for Hepatitis B carriers. At clinician's discretion, after consideration of risk factors including long term prescription medication.

**Dysphagia & Aspiration**

- **Cardiovascular Disease**
  - Conduct annual cardiovascular risk assessment.
  - Specific syndromes and neurologic medications may increase risk for cardiovascular disease.

**Osteoporosis**

- **Eye Examination**
  - Consider BMD testing at any age if risk factors are present. Risk factors include long-term polypharmacy (particularly anticonvulsants), mobility impairments, hypoestrogenic, hypothyroid, lack of physical activity, vitamin D deficiency.

**Glucoma Assessment**

- **Hearing Assessment**
  - Assess annually for hearing changes. If changes are present, refer to audiologist for a full screen as needed.

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1. Reviewed sources: Massachusetts Health Quality Partnership (MHQP) 2017 Adult Preventive Care Recommendations; Consensus guidelines for primary health care of adults with developmental disabilities, Canadian Family Physician, Vol.57 2011; US Preventive Services Task Force Guidelines; CDC 2017 Adult Immunization Schedule. Items in bold differ from adult care recommendations in order to reflect unique health concerns of people with ID.
Part 2: Exploration of Interprofessional Teams
Provide medical care including prescribing or administering meds.
- Doctors (Primary Care, Specialists), Nurses, Dentists

Social Supports
Provide social interaction, emotional support, and help with ADLs. May or may not have additional training
- UAPs in group homes or day programs*, family, community workers

Licensed Medical Personnel
Interdisciplinary Care for Individuals w/ IDD
*Can give meds w/ MAP training

Community Services

Help coordinate and provide community resources for individual & family.
- Dept. of Developmental Services, Case Managers, Care Coordinators

Licensed Allied Health
Provide therapeutic intervention in a specific area, no meds.
- PT, OT, SLP, Nutrition, Psychology
Interprofessionalism is key!

What can these potential team members provide?

- Services that you wouldn’t otherwise be able to provide
- Different breadth of knowledge
- Different resources
Part 3: Population Health
Advocacy for People with IDD
● On what levels can we advocate?
  ○ Personal
  ○ Professional
  ○ Political

● Largest impact of healthcare changes
  ○ Lawsuits against the state of MA guaranteed future funding
    ■ Rolland v. Commonwealth - 1998
    ■ Olmstead v. LC 1999 - National
    ■ Ricci v. Okin 1972

● What can we advocate for?
  ○ Reducing disparities in access to care
  ○ Improve quality of care
  ○ “Behavioral issues” are not always expression of disability
  ○ Communication
  ○ Longer appointments with adequate reimbursement
  ○ Funding for IDD community resources (schools, day programs, etc)
Advocacy Groups
Key Takeaways: Areas for Provider Advocacy

The needs of patients with I/DD differ from those of the general population

- Higher risk of aspiration pneumonia/speech and swallow disorders
- Special requirements for the dispensing of medication
- Polypharmacy with severe risk of adverse side effects
  - Constipation
- Speaking to patients directly and listening to caregivers
- Patient transportation
- Patient goals and capabilities
  - Artwork
  - Employment
  - Mobility
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- Hogan Developmental Center
References


Thank you!